**SECTION C: PEDIATRIC ENDOCRINOLOGY**

1. **Do you have a Pediatric Endocrinology program?**

**(ENDO\_HAVEPROGRAM)**

* Yes
* No – Skip to Section D

**When responding to questions in this section, your hospital must consult with the chief of service (or equivalent) of your Pediatric Endocrinology program to ensure that answers are accurate and consistent with both the care delivered and the intent of the survey.**

**As data are reviewed, U.S. News may have questions about responses to individual questions or about an entire submission. To ensure communication with the appropriate clinical leader, please provide the following information about the chief of service (or equivalent) for your Pediatric Endocrinology program.**

 **Full name:**

|  |
| --- |
| **(ENDO\_DIR\_NAME)** |

 **Title:**

|  |
| --- |
| **(ENDO\_DIR\_TITLE)** |

 **Email:**

|  |
| --- |
| **(ENDO\_DIR\_EMAIL)** |

 **Preferred phone:**

|  |
| --- |
| **(ENDO\_DIR\_PHONE)** |

REQUIRED: IF NAME, TITLE, EMAIL, OR PHONE=BLANK, DISPLAY: “A response is required for [Name/Title/Email/Phone] prior to submitting the survey. Click “OK” to continue with the survey and answer this question later. Click “Cancel” to provide a response to this question now.”

**C1.1 Are you submitting jointly with a Pediatric Endocrinology program at another hospital?**

**(ENDO\_JOINTSUB)**

* + Yes – Go to Question C1.2
	+ No – Skip to Question C2

**C1.2 If yes, what is the name of the Pediatric Endocrinology program you are reporting jointly with?** Please note that joint submissions must be reviewed and approved before they are allowed. Before submitting your survey, please contact RTI at PediatricHospSurvey@rti.org to discuss your joint submission request unless you already have received permission to jointly submit data in this specialty. As noted in the instructions for joint reporting, if you are granted permission, only the primary hospital in the joint reporting relationship will be allowed to report data for this specialty.

|  |
| --- |
| **(ENDO\_JOINTSUB\_NAME)** |

1. **Please indicate the total number of attending/on-staff physicians (excluding fellows)[[1]](#footnote-2) who *are currently members of the medical staff* in your Pediatric Endocrinology program in the following categories.** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Total Physicians** |
| a. | Pediatric endocrinologists (board certified/board eligible by the American Board of Pediatrics or the American Osteopathic Board of Pediatrics with subspecialty certification in pediatric endocrinology) **(ENDO\_PHYSICIANS\_ENDO\_** | \_\_\_\_\_\_\_\_**TOT)** |
| b. | Other attending/on-staff physicians (include all other attending/on-staff physicians who are **not** subspecialty certified/ board eligible in pediatric endocrinology) **(ENDO\_PHYSICIANS\_OTHER\_** | \_\_\_\_\_\_\_\_**TOT)** |

NOTES: C2x should be whole number only. Do not allow decimals.

***Note: The preceding questions are used to determine eligibility for Pediatric Endocrinology. If you leave any part of these questions blank, your hospital will be considered ineligible for the rankings in Pediatric Endocrinology.***

1. **Please indicate the total number of nurse practitioners and physician assistants who currently work in or directly support your Pediatric Endocrinology program.** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Total** **Staff** |
| a. | Nurse practitioners**(ENDO\_NP\_** | \_\_\_\_\_\_\_\_**TOT)** |
| b. | Physician assistants **(ENDO\_PA\_** | \_\_\_\_\_\_\_\_**TOT)** |

NOTES: C3x should be whole number only. Do not allow decimals.

1. **Please indicate the total number of RN FTEs actually spent in outpatient clinical care of Pediatric Endocrinology patients, including Endocrinology testing. [**Do not include Nurse Practitioners already counted in C3. Due to ongoing nursing shortages, contract nurses should be included in your counts of clinical RNs.] [If none, please enter 0.]

**\_\_\_\_\_\_** Number of RN FTEs spend in outpatient clinical care of Pediatric Endocrinology patients

**(ENDO\_NURSE\_TOT)**

NOTES: C4 is numeric entry (decimals are allowed).

VALIDATE: If C4 is not numeric: “C4: Please enter a numeric value.”

1. **How many FTEs of the following health care staff provide diabetes education to patients in your Pediatric Endocrinology program and currently have Certified Diabetes Care and Education Specialist (CDCES) certification?** [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  |  | **FTEs with CDCES certification**  |
| a. | Nurses **(ENDO\_SUPPORT\_** |  | **\_\_\_\_\_****NURSE\_CDE)** |
| b. | Dietitians **(ENDO\_SUPPORT\_** |  | **\_\_\_\_\_****DIET\_CDE)** |
| c. | Others (e.g., Pharmacists, Social Workers, Psychologists) **(ENDO\_SUPPORT\_** |  | **\_\_\_\_\_****OTH\_CDE)** |
| d. | Certified exercise physiologist or Physical therapist **(ENDO\_SUPPORT\_** |  | **\_\_\_\_\_****EXER\_CDE)** |

NOTES: C5x is numeric entry (decimals are allowed).

VALIDATE: If C5x is not numeric: “C5x: Please enter a numeric value.”

1. **Please indicate whether your program has at least 1 fulltime equivalent (FTE)[[2]](#footnote-3) staff in each category below currently *dedicated* to the care of inpatient or outpatient pediatric Endocrinology patients.**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Social workers  | **○** | **○** |
|  | **(ENDO\_SUPPORT\_** | **SOC\_FTE)** |
| b. | Psychologists  | **○** | **○** |
|  | **(ENDO\_SUPPORT\_** | **PSYC\_FTE)** |
| c. | Community health workers or patient navigators  | **○** | **○** |
|  | **(ENDO\_SUPPORT\_** | **COMM\_FTE)** |

1. **In the last calendar year, did the following health care staff provide on-site or telehealth services to your Pediatric Endocrinology patients?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Genetic counselors **(ENDO\_SUPPORT\_PERSONNEL\_GEN)** | **○** | **○** |
| b. | Psychiatrist **(ENDO\_SUPPORT\_PERSONNEL\_PSYCH)** | **○** | **○** |
| c. | Pharmacist **(ENDO\_SUPPORT\_PERSONNEL\_PHARM)** | **○** | **○** |

1. **This question has been removed from the survey.**

1. **Does your Pediatric Diabetes program provide the following services onsite?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Certified pump educators (CPEs) who are members of your staff[[3]](#footnote-4) who provide pump training in house to patient families **(ENDO\_SERVICES\_PUMPCERT)** | **○** | **○** |
| b. | CGM trainers who are members of your staff5 who provide CGM training to patient families **(ENDO\_SERVICES\_CGMCERT)** | **○** | **○** |
| c. | Formal diabetes education program for school nurses through a yearly school nurse education conference **(ENDO\_SERVICES\_SCHOOLEDUC)** | **○** | **○** |
| d. | A specified RN or CDCES who is responsible for advising and supporting schools in safe management of diabetes **(ENDO\_SERVICES\_SCHOOLADVISOR)** | **○** | **○** |

1. **Did your Pediatric Diabetes program staff (physicians, physician assistants, nurse practitioners, clinical nurses, and diabetes educators) take a leadership role in organizing and running a Diabetes Camp in the last year?**

**(ENDO\_DBTES\_CAMP)**

* Yes
* No
1. **Did any of your Pediatric Diabetes program staff (physicians, physician assistants, nurse practitioners, clinical nurses, or diabetes educators) take a leadership role in a formal advocacy effort[[4]](#footnote-5) supporting the rights of patients with diabetes with local, state, and/or federal government in the last year?**

**(ENDO\_PATIENT\_RIGHTS)**

* Yes
* No
1. **Has your Pediatric Diabetes program hosted or been actively involved in organizing a diabetes-specific support group at your hospital or in your community in the last calendar year?**

**(ENDO\_SUPPORT\_GROUP)**

* Yes
* No
1. **Has your Pediatric Diabetes program hosted or been actively involved in organizing a diabetes-specific technology (pumps, CGM, social networking websites, diabetes apps, telemedicine) education program to increase awareness and access to new technology to decrease health disparity for your patients in the last calendar year?**

**(ENDO\_SUPPORT\_TECH)**

* Yes
* No
1. **Did your diabetes education program have “recognition status” from the American Diabetes Association (ADA) or the American Association of Diabetes Educators (AADE) as of December 31, 2024?**

**(ENDO\_AADE\_RECOG)**

* Yes
* No
1. **Does your Diabetes Program administer a formal, written assessment of diabetes management knowledge after initial education and at least yearly thereafter?**

**(ENDO\_ED\_ASSESSMENT)**

* Yes
* No – Skip to Question C16

**C15.1 Is this assessment recorded in your electronic health records?**

**(ENDO\_EDASSESS\_RECORDS)**

* Yes
* No
1. **How many times were diabetes patients on insulin therapy (see code list – patients must have diabetes diagnosis AND be treated with insulin) admitted as inpatients to other services (e.g., surgery, transplant, cystic fibrosis) in the last calendar year?** [Do not include any patients who stay less than 24 hours.][If none, please enter 0.]

**\_\_\_\_\_\_** Admissions of diabetes inpatients treated with insulin admitted to other services **(ENDO\_OTHERSVC\_ADMIT)**

NOTES: C16 should be whole number only. Do not allow decimals.

SKIP LOGIC: IF C16 >0, ASK C16.1; ELSE, GO TO C17.

**C16.1 How many of these admissions (from C16) were seen by a clinical member of your Pediatric Diabetes program for evaluation, assistance with patient management, or teaching (e.g., pump education, diet consultation, medication management, etc.)?** [If none, please enter 0.]

**\_\_\_\_\_\_**Admissions seen by providers in the Pediatric Diabetes program **(ENDO\_OTHERSVC\_SEEN)**

NOTES: C16.1 should be whole number only. Do not allow decimals.

VALIDATE: IF C16.1 > C16, DISPLAY: The number of admissions in C16.1 cannot be greater than the number of admissions in C16.

1. **In the last year, has your Pediatric Diabetes program provided a formal written transition program to prepare pediatric patients over a period of time (6 months or more) for the transition to an adult diabetes physician or program?**

**(ENDO\_TRANSITION)**

* Yes
* No – Skip to Question C18

**C17.1 Are the steps for transition of each patient recorded in your electronic health records?**

**(ENDO\_TRANS\_PREP)**

* Yes
* No
1. **This question has been removed from the survey.**
2. **Which of the following elements are always included in the summary available to patients after outpatient visits (including telemedicine visits) in your Pediatric Diabetes program? (**Check all that apply)
* Complete insulin dosages (e.g., Basal dose/pump rates; bolus dosing parameters; fixed insulin doses) **(ENDO\_SUMMARY\_DOSAGES)**
* MDI dosages for pump failure, for those on insulin pumps **(ENDO\_SUMMARY\_MDI)**
* Glucose monitoring recommendations including periodic self-assessment of glycemia patterns **(ENDO\_SUMMARY \_GLUCOSE)**
* A1c value from within 2 weeks of visit date and/or percent of time “in range” (70 – 180 mg/dl ) or Glucose Management Indicator (GMI) from at least 2 weeks of CGM data **(ENDO\_SUMMARY­\_A1C)**
* Follow up visit instructions **(ENDO\_SUMMARY­\_NEXTVISIT)**
* Information on when and how to contact the Diabetes Center **(ENDO\_SUMMARY \_INFO)**
* Referrals made for laboratory, ophthalmological, dental, mental health before the next visit **(ENDO\_SUMMARY\_LAB)**
* Behavioral Goals **(ENDO\_SUMMARY\_BEH**)
* None of the above **(ENDO\_SUMMARY\_NONE)**
1. **Does your Pediatric Diabetes program have a clinical database of attributes of current, active diabetes patients that you use for quality assessment and improvement that would allow you to determine, for example, the mean and median value for the most recent outpatient Hemoglobin A1c for all active patients from 8-10 years of age with Type 1 diabetes (see code list)?**

**(ENDO\_DATABSE)**

* Yes
* No
1. **This question has been removed from the survey.**
2. **Does your Pediatric Diabetes program have written consensus protocols or guidelines for the following?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Glucagon minidose for families **(ENDO\_PROTOCOL\_GLUCAGON)** | **○** | **○** |
| b. | Periodic screening for complications of diabetes in the outpatient clinic **(ENDO\_PROTOCOL\_SCREENING)** | **○** | **○** |
| c. | Evaluation of hyperglycemia in critically ill inpatients (without baseline diabetes) **(ENDO\_PROTOCOL\_HYPERGLYCEMIA)** | **○** | **○** |
| d. | Outpatient management of Type 2 diabetes patients **(ENDO\_PROTOCOL\_TYPE2)** | **○** | **○** |
| e. | Outpatient management of “pre-diabetes” patients who typically have obesity and insulin resistance, which includes guidelines for screening for co-morbidities including hypertension, dyslipidemia, non-alcoholic steatohepatitis, orthopedic disease, and sleep apnea **(ENDO\_PROTOCOL\_PREDIABETES)** | **○** | **○** |
| f. | Inpatient management of Hyperglycemic Hyperosmolar Syndrome**(ENDO\_PROTOCOL\_HSS)** | **○** | **○** |
| g. | Guidelines for outside physicians and emergency departments for recognition and initial management of diabetes and DKA**(ENDO\_PROTOCOL\_INITIAL\_MANAGE)** | **○** | **○** |
| h. | Inpatient management of patients using insulin pumps **(ENDO\_PROTOCOL\_INPTPUMP)** | **○** | **○** |
| i. | Inpatient glucose assessments for patients using CGM **(ENDO\_PROTOCOL\_CGM)** | **○** | **○** |
| j. | Education on islet cell antibody testing for first degree relatives of patients with type 1 diabetes **(ENDO\_PROTOCOL\_EDUTEST)** | **○** | **○** |

1. **This question has been removed from the survey.**
2. **This question has been removed from the survey.**
3. **Does your Pediatric Diabetes program have a regularly scheduled interdisciplinary care conference involving Pediatric Endocrinologists, Dietitians, Social Workers or Psychologists, and Diabetes Nurse Educators to discuss diabetes outpatients (see code list) with consistently elevated A1c, recurrent DKA, frequent severe hypoglycemia, or significant psychosocial challenges?**

**(ENDO\_SUBOPTCOTR\_DIABE)**

* Yes
* No (Skip to C27)
1. **During the last calendar year, approximately how often did the interdisciplinary care conferences occur?**

 **(ENDO\_CONF\_FREQ)**

* Once or twice during the year
* Every two to three months
* Once a month
* Twice a month
* Once a week
* Not Applicable
1. **Does your Pediatric Endocrinology program have an EMR dashboard or reporting mechanism to identify which patients should get intensified diabetes management?**

**(ENDO\_HIGHRISK)**

* Yes
* No

**C27.1 Does your Pediatric Endocrinology program have a formal intensified diabetes management protocol for patients who need this (Such as more frequent contacts and/or more support?**

**(ENDO\_HIGHRISK\_EMR)**

* Yes
* No
1. **Does your Pediatric Endocrinology program interact with your institution’s clinical laboratory or pathology service to review laboratory findings, problems, and updates?**

**(ENDO\_LAB\_INTERACT)**

* On a regular basis (an established frequency or routine)
* As needed
* Never or not at all

**C28.1 What was the total number of patient admissions/visits to your Pediatric Diabetes program that had each of the following primary diagnoses in the last calendar year?** [Note that your numbers may include all pediatric patients seen for care that are < 19 years of age.] [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Total patient admissions/visits** |
| a.  | Outpatient visits (in-person and virtual telehealth visits) with Type 1 diabetes (see code list) **(ENDO\_OUT\_** | \_\_\_\_\_\_\_\_**TOT1)** |
| b.  | Outpatient visits (in-person and virtual telehealth visits) with Type 2 diabetes (see code list) **(ENDO\_OUT\_** | \_\_\_\_\_\_\_\_**TOT2)** |
| c.  | Inpatient admissions with Type 1 diabetes (see code list) admitted for diabetes-related causes (hyperglycemia, DKA) **(ENDO\_IN\_** | \_\_\_\_\_\_\_\_**TOT1)** |
| d.  | Inpatient admissions with Type 2 diabetes (see code list) admitted for diabetes-related causes (hyperglycemia, DKA) **(ENDO\_IN\_** | \_\_\_\_\_\_\_\_**TOT2)** |

NOTES: C28.1x should be whole number only. Do not allow decimals.

**C28.2 How many unique patients with a genetically confirmed (in the patient or the patient’s family member) form of genetic diabetes (e.g., maturity onset diabetes of the young (MODY) or neonatal diabetes mellitus (NDM) were seen in outpatient clinic by providers in your Pediatric Diabetes program in the last calendar year?** [Note: The codes used for this question include a wide array of diagnoses beyond MODY. Please review cases identified when using these codes and only include those that meet the requirements for MODY (e.g., “Maturity onset diabetes mellitus in young, Maturity onset diabetes of youth, Maturity-onset diabetes of the young”).]

**\_\_\_\_\_\_** Unique patients seen with genetic forms of diabetes **(ENDO\_OUT\_GENETICPRIV)**

NOTES: C28.2 should be whole number only. Do not allow decimals.

**C28.3 This question has been removed from the survey.**

**C28.4 This question has been removed from the survey.**

1. **Do you ask at each diabetes outpatient clinic visit about the number of hospital admissions, emergency department visits, or urgent care visits since the last diabetes outpatient visit?** [Note: To answer “yes” you must include admissions and visits at your hospital and at other facilities and offices from patient charts in your counts.]

**(ENDO\_OTHERVISITS\_ASK)**

* Yes
* No (Skip to C29.2)

**C29.1 Does your EMR have a field (such as an Epic FlowSheet) to track the number of hospital admissions, emergency department visits, and urgent care visits since the last diabetes outpatient visit?** To answer “yes” this must **not** be a free-text field.

**(ENDO\_OTHERVISITS\_TRACK)**

* Yes
* No

**C29.2 Indicate the number of unique primary diabetes**[[5]](#footnote-6) **care patients who are < 19 years of age in each of the following categories seen in your Pediatric Diabetes program by insurance type (private or commercial insurance versus Medicaid only)[[6]](#footnote-7).** [If none, please enter 0.]

When identifying data for your response to this question, please:

* Access or filter data to outpatient visits (in-person and virtual telehealth visits), inpatient records, or ER and urgent care visits (as requested in the questions below);
* Remove any patients with age > 19 on the date of the visit;
* Merge/join the ICD-10 code lists provided for each population of interest;
* Keep only patients with a date of diagnosis or initial visit date before January 1, 2024;
* De-duplicate by unique patient identifier to obtain unique patient count; and
* Flag Medicaid / Private insurance category as payer type at last visit.

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Unique *Private Insurance* Patients** | **Unique *Medicaid* Patients** |
| a.  | Primary diabetes care pediatric **outpatients** in your practice for over one year and seen 2 or more times in the last calendar year with Type 1 diabetes (see code list) **(ENDO\_OUTPAT1\_\_** | \_\_\_\_\_\_\_\_**PRIVATE)** | \_\_\_\_\_\_\_\_**MEDICAID)** |
| b.  | Primary diabetes care pediatric **outpatients** in your practice for over one year and seen 2 or more times in the last calendar year with Type 2 diabetes (see code list) **(ENDO\_OUTPAT2\_** | \_\_\_\_\_\_\_\_**PRIVATE)** | \_\_\_\_\_\_\_\_**MEDICAID)** |
| c.  | Number of unique patients in C29.2a admitted for diabetes-related causes (hypoglycemia, DKA) **(ENDO\_INPAT1** | \_\_\_\_\_\_\_\_**PRIVATE)** | \_\_\_\_\_\_\_\_**MEDICAID)** |
| d.  | Number of unique patients in C29.2b admitted for diabetes-related causes (hypoglycemia, DKA) **(ENDO\_INPAT2** | \_\_\_\_\_\_\_\_**PRIVATE)** | \_\_\_\_\_\_\_\_**MEDICAID)** |
| e.  | Number of patients in C29.2a seen in emergency room or urgent care[[7]](#footnote-8) for diabetes-related causes (hypoglycemia, DKA) **(ENDO\_ER1** | \_\_\_\_\_\_\_\_**PRIVATE)** | \_\_\_\_\_\_\_\_**MEDICAID)** |
| f.  | Number of patients in C29.2b seen in emergency room or urgent care[[8]](#footnote-9) for diabetes-related causes (hypoglycemia, DKA) **(ENDO\_ER2** | \_\_\_\_\_\_\_\_**PRIVATE)** | \_\_\_\_\_\_\_\_**MEDICAID)** |

NOTES: C29.2x should be whole number only. Do not allow decimals.

VALIDATE: IF C29.2x IS BLANK, DISPLAY: “C29.2x: If none, please enter 0.”

 IF C29.2c > C29.2a DISPLAY: “Type 1 patients admitted for diabetes-related causes (C29.2c) cannot be greater than total Type 1 primary diabetes care pediatric outpatients (C29.2a).”

 IF C29.2d > C29.2b, DISPLAY: “Type 2 patients admitted for diabetes-related causes (C29.2d) cannot be greater than total Type 2 primary diabetes care pediatric outpatients (C29.2b).”

 IF C29.2e > C29.2a, DISPLAY: “Type 1 patients seen in ER or urgent care (C29.2e) cannot be greater total Type 1 primary diabetes care pediatric outpatients (C29.2a).”

 IF C29.2f > C29.2b, DISPLAY: “Type 2 patients seen in ER or urgent care (C29.2f) cannot be greater than total Type 2 primary diabetes care pediatric outpatients (C29.2b).”

SKIP LOGIC: IF C29.2a1 + C29.2a2 + C29.2b1 + C29.2b2 > 0, ASK C30 – C36. ELSE, GO TO C37.

1. **What percentage of all primary care diabetes patients (see C29.2a and C29.2b) that are < 19 years of age being treated by your Pediatric Endocrinology Program have had a face-to-face or telehealth visit of the following type in the last calendar year?**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  |  | **0-49%** | **50-69%** | **70-84%** | **85-100%** |
| a.  | Medical Nutrition Therapy with a Registered Dietician **(ENDO\_ENCOUNTER\_MNT)** | **○** | **○** | **○** | **○** |
| b.  | Diabetes Education **(ENDO\_ENCOUNTER\_CDE)** | **○** | **○** | **○** | **○** |
| c.  | Social Worker, Psychologist, or Mental Health Professional assessment **(ENDO\_ENCOUNTER\_SW)** | **○** | **○** | **○** | **○** |

1. **What percentage of primary care diabetes patients (see C29.2a and C29.2b) that are < 19 years of age seen in the last calendar year that meet the criteria described below had completed the following tests?** [Notes: (1) We recommend that you consult your inpatient and outpatient EMR records as well as physician billing to determine whether each test occurred; if your hospital tracks these data in a local database, that may be consulted as well. (2) When submitting your survey, each hospital will be required to create and upload a deidentified table of patient data from your EMR or other records that shows the values for each requested element. The file should include a record identifier, the date of service (which can be month or quarter if needed) for any test or procedure listed, and the value of the information requested. If totals across a group of patients are requested to respond to the survey item, please also show your work in this file with totals and formulas displayed. This information will be used to check your responses to this question.]

|  |
| --- |
| **Type 1 diabetes (see C29.2a)** |
|  |  | **Percent of Type 1 diabetes patients**  |
| a.  | Percentage of primary care Type 1 diabetes patients (see C29.2a) that had TSH documented in their patient medical chart at some point in the last 2 calendar years **(ENDO\_TYPE1\_TSH)** | \_\_\_\_\_\_\_\_% |
| b.  | Percentage of primary care Type 1 diabetes patients (see C29.2a), who are >11 and < 19 years of age, who have had a lipid profile performed in the last 3 calendar years **(ENDO\_TYPE1\_LIPID)** | \_\_\_\_\_\_\_\_% |
| c.  | Percentage of primary care Type 1 diabetes patients (see C29.2a), who are >11 and < 19 years of age and with a duration of diabetes over 5 years, who have received a microalbuminuria screening in the last calendar year **(ENDO\_TYPE1\_MICROALB)** | \_\_\_\_\_\_\_\_% |
| d.  | Percentage of primary care Type 1 diabetes patients (see C29.2a), who are >11 and <19 years of age, with a duration of diabetes over 5 years, who have received a dilated retinal or non-mydriatic camera examination in the last 2 calendar years. An official report or a parent report of this evaluation including the month and year of the exam must be recorded in the medical record. **(ENDO\_TYPE1\_DILATED)** | \_\_\_\_\_\_\_\_% |
| **Type 2 diabetes (see C29.2b)[[9]](#footnote-10)** |
|  |  | **Percent of Type 2 diabetes patients** |
| e.  | Percentage of primary care Type 2 diabetes patients (see C29.2b) who have had a lipid profile performed in the last calendar year. **(ENDO\_TYPE2\_LIPID)** | \_\_\_\_\_\_\_\_% |
| f.  | Percentage of primary care Type 2 patients (see C29.2b) who have had a microalbuminuria screening in the last calendar year. **(ENDO\_TYPE2\_MICROALB)** | \_\_\_\_\_\_\_\_% |
| g.  | Percentage of primary care Type 2 patients (see C29.2b) who have received a dilated retinal or non-mydriatic camera examination in the last 2 calendar years. An official report or a parent report of this evaluation including the month and year of the exam must be recorded in the medical record. **(ENDO\_TYPE2\_DILATED)** | \_\_\_\_\_\_\_\_% |

NOTES: C31x is numeric entry (decimals are allowed).

VALIDATE: 0 ≤ C31x ≤ 100. ELSE DISPLAY: “C31x: Please enter a numeric value between 0 and 100.”

 If C31x is not numeric: “C31x: Please enter a numeric value.”

1. **Of the unique primary care Type 1 diabetes pediatric patients (reported in C29.2a) that are < 19 years of age who have been treated for the past 12 months or longer, and who have NOT met the criteria for adequate diabetes management[[10]](#footnote-11), what percentage were scheduled for and what percentage attended four or more diabetes outpatient clinic visits[[11]](#footnote-12) in the last calendar year? Include only “primary care Type 1 diabetes patients” (i.e., patients in the C29.2a group), not all type 1 diabetes patients.** [Note that outpatient visits may include in-person and telehealth visits as long as at least 1 visit annually for these patients is conducted in-person.]

\_\_\_\_\_\_\_\_a. % Scheduled for 4 or more outpatient clinic visits **(ENDO\_SCH\_4MOREVISIT)**

\_\_\_\_\_\_\_\_b. % Attended 4 or more outpatient clinic visits **(ENDO\_PCT\_4MOREVISIT)**

NOTES: C32x is numeric entry (decimals are allowed).

VALIDATE: 0 ≤ C32x ≤ 100. ELSE DISPLAY: “C32x: Please enter a numeric value between 0 and 100.”

 IF C32b > C32a, DISPLAY: “C32: Please check your responses. The percent of patients that attended 4 or more visits cannot be greater than the percent of patients scheduled for 4 or more visits.”

 If C32x is not numeric: “C32x: Please enter a numeric value.”

**C32.1 This question has been removed from the survey.**

**C32.2 This question has been removed from the survey**

1. **How many of the unique primary Type 1 diabetes care pediatric patients (as defined in question C29.2a) who are < 19 years of age used an insulin pump in the last calendar year by insurance type? Include only “primary Type 1 diabetes care patients” (i.e., patients in the C29.2a group), not all type 1 diabetes patients.**

\_\_\_\_\_\_\_\_a. Number of unique private insurance patients on insulin pump **(ENDO\_INSULIN\_PUMP\_PRIV)**

\_\_\_\_\_\_\_\_b. Number of unique Medicaid patients on insulin pump **(ENDO\_INSULIN\_PUMP\_MED)**

NOTES: C33x should be whole number only. Do not allow decimals.

VALIDATE: IF C33a > C29.2a DISPLAY: “Please check your responses. (Private Insurance) Type 1 patients on a hybrid closed loop pump (C33a) cannot be greater than total Type 1 primary diabetes care pediatric outpatients (C29.2a).”

 IF C33b > C29.2a DISPLAY: “Please check your responses. (Medicaid) Type 1 patients on a hybrid closed loop pump (C33b) cannot be greater than total Type 1 primary diabetes care pediatric outpatients (C29.2a).”

**C33.1 Of the unique primary Type 1 diabetes care pediatric patients using insulin pumps (as reported in C33), how many used a hybrid closed-loop pump or closed-loop pump in the last calendar year by insurance type?** [Note that both FDA-approved and non-approved pumps may be included. Pumps that only suspend insulin delivery for low blood glucose should not be included.] Include only patients who are counted in C33, not all type 1 diabetes patients.

**\_\_\_\_\_\_**\_\_ a. Unique patients on a hybrid closed-loop pump or closed-loop pump for private insurance patients (**ENDO\_CLP\_PRIV)**

**\_\_\_\_\_\_**\_\_ b. Unique patients on a hybrid closed-loop pump or closed-loop pump for Medicaid patients **(ENDO\_CLP\_MEDI)**

NOTES: C33.1x should be whole number only. Do not allow decimals.

VALIDATE IF C33.1a > C33a DISPLAY: “Please check your responses. (Private Insurance) Type 1 patients on a hybrid closed loop pump (C33.1a) cannot be greater than total Type 1 patients on an insulin pump (C33a).”

 IF C33.1b > C33b DISPLAY: “Please check your responses. (Medicaid) Type 1 patients on a hybrid closed loop pump (C33.1b) cannot be greater than total Type 1 patients on an insulin pump (C33b).”

1. **What percentage of your primary diabetes care (Type 1 and Type 2) patients (see C29.2a and C29.2b) aged 13 to < 19 years of age were screened for depression using a validated depression screening tool (such as the Beck Depression Inventory-II, PHQ-9, CDI) in the last calendar year? Include only “primary Type 1 and Type 2 diabetes care patients” (i.e., patients in the C29.2a and C29.2b groups), not all diabetes patients.**

**(ENDO\_DEPRESSION)**

* + 0-49%
	+ 50-69%
	+ 70-84%
	+ 85-100%
* NA. Did not see Type 1 or Type 2 diabetes patients aged 13 to < 19 in the last calendar year. **(ENDO\_DEPRESSION\_NA)**

NOTES: N/A should be mutually exclusive (i.e. cannot be selected with other responses).

**C34.1** **What percentage of your primary diabetes care (Type 1 and Type 2) patients (see C29.2a and C29.2b) who had a score indicative of moderate or severe depressive symptoms or endorsed self-harm on their depression screen (see C34) either were referred for assessment by a mental health professional (social worker, licensed counselor, psychologist, or psychiatrist) or are already under the care of a mental health professional? Include only patients who are counted in C34, not all diabetes patients.**

**(ENDO\_DEPRESSION\_FOLLOWUP)**

* + 0-49%
	+ 50-69%
	+ 70-84%
	+ 85-100%
* NA. Did not screen Type 1 or Type 2 diabetes patients for depression in the last calendar year. **(ENDO\_DEPRESSION\_FOLLOWUP\_NA)**

NOTES: N/A should be mutually exclusive (i.e. cannot be selected with other responses).

1. **This question has been removed from the survey.**

**C35.1 Of the unique pediatric primary care Type 1 diabetes outpatients (see C29.2a) < 19 years of age, what was the volume of patients seen by your Pediatric Diabetes program by each age group listed below[[12]](#footnote-13) and the number of patients achieving optimal Hemoglobin A1c control (defined as having at least one Hemoglobin A1c at or below 7.5% in the last calendar year)? Please report the values separately for patients covered by private/commercial insurance versus Medicaid only[[13]](#footnote-14) for each of the defined age groups.** [When submitting your survey, each hospital will be required to create and upload a deidentified table of patient data from your EMR or other records that shows the values for each requested element. For this question, the file should include a single row for each patient with a record identifier, the date of test value (which can be month or quarter if needed), the age, insurance type, and lowest A1c value for the last calendar year. In the spreadsheet, please also show your work for the calculations for patient volume and patients achieving optimal control. This information will be used to check your responses to this question.]

When identifying data for your response to this question, please:

* Include only primary care type 1 outpatients reported in C29.2a;
* Calculate age as date of last visit minus date of birth;
* Flag each age category (0-7, 8-13, 14-18);
* Merge/join Type 1 outpatient data with A1c value data;
* Flag A1c values less than or equal to 7.5%; and
* Document all of the above data in a spreadsheet as directed in the instructions for this question to be submitted with your survey.

**Volume of Treated Primary Care Patients**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Unique primary care Type 1 Patients** **on Private Insurance treated** | **Unique primary care Type 1 Patients** **on Medicaid Insurance treated** |
| a.  | 0-7 years old**(ENDO\_A1C\_AGE7\_** | \_\_\_\_\_\_\_\_**TREAT\_PRIVATE)** | \_\_\_\_\_\_\_\_**TREAT\_MEDICAID)** |
| b.  | 8-13 years old**(ENDO\_A1C\_AGE13\_** | \_\_\_\_\_\_\_\_**TREAT\_PRIVATE)** | \_\_\_\_\_\_\_\_**TREAT\_MEDICAID)** |
| c.  | 14-18 years old**(ENDO\_A1C\_AGE18\_** | \_\_\_\_\_\_\_\_**TREAT\_PRIVATE** | \_\_\_\_\_\_\_\_**TREAT\_MEDICAID)** |

**Patients Achieving Optimal Control**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Unique Type 1 Patients** **on Private Insurance** **who achieve** **optimal A1c control** | **Unique Type 1 Patients** **on Medicaid Insurance** **who achieve** **optimal A1c control** |
| d.  | 0-7 years old**(ENDO\_A1C\_AGE7\_** | \_\_\_\_\_\_\_\_**OPTIMAL\_PRIVATE)** | \_\_\_\_\_\_\_\_**OPTIMAL\_MEDICAID)** |
| e.  | 8-13 years old**(ENDO\_A1C\_AGE13\_** | \_\_\_\_\_\_\_\_**OPTIMAL\_PRIVATE)** | \_\_\_\_\_\_\_\_**OPTIMAL\_MEDICAID)** |
| f.  | 14-18 years old**(ENDO\_A1C\_AGE18\_** | \_\_\_\_\_\_\_\_**OPTIMAL\_PRIVATE)** | \_\_\_\_\_\_\_\_**OPTIMAL\_MEDICAID)** |

NOTES: C35.1x1 and C35.1x2 should be whole number only. Do not allow decimals.

VALIDATE: IF (C35.1a1+ C35.1b1+C35.1c1) > C29.2a1, DISPLAY: “Please check your responses. (Private Insurance) Type 1 patients by age (C35.1a + C35.1b +C35.1c) cannot be greater than total Type 1 primary diabetes care pediatric outpatients (C29.2a).”

 IF (C35.1a2+ C35.1b2+C35.1c2) > C29.2a2, DISPLAY: “Please check your responses. (Medicaid) Type 1 patients by age (C35.1a + C35.1b +C35.1c) cannot be greater than total Type 1 primary diabetes care pediatric outpatients (C29.2a).”

 IF C35.1d1 > C35.1a1, DISPLAY: “C35.1d (Private Insurance): The number of patients 0-7 years old who achieve optimal control (C35.1d) cannot be greater than the total number of patients 0-7 years old (C35.1a).”

 IF C35.1d2 > C35.1a2, DISPLAY: “C35.1d (Medicaid): The number of patients 0-7 years old who achieve optimal control (C35.1d) cannot be greater than the total number of patients 0-7 years old (C35.1a).”

 IF C35.1e1 > C35.1b1, DISPLAY: “C35.1e (Private Insurance): The number of patients 8-13 years old who achieve optimal control (C35.1e) cannot be greater than the total number of patients 8-13 years old (C35.1b).”

 IF C35.1e2 > C35.1b2, DISPLAY: “C35.1e (Medicaid): The number of patients 8-13 years old who achieve optimal control (C35.1e) cannot be greater than the total number of patients 8-13 years old (C35.1b).”

 IF C35.1f1 > C35.1c1, DISPLAY: “C35.1f (Private Insurance): The number of patients 14-18 years old who achieve optimal control (C35.1f) cannot be greater than the total number of patients 14-18 years old (C35.1c).”

 IF C35.1f2 > C35.1c2, DISPLAY: “C35.1f (Medicaid): The number of patients 14-18 years old who achieve optimal control (C35.1f) cannot be greater than the total number of patients 14-18 years old (C35.1c).”

**C35.2 This question has been removed from the survey.**

**C35.3 This question has been removed from the survey.**

**C35.4 This question has been removed from the survey.**

1. **This question has been removed from the survey.**
2. **This question has been removed from the survey.**
3. **Does your pediatric Diabetes Program track the number of school days that are missed for a diabetes-related problem (hypoglycemia, hyperglycemia and/or DKA) by children and adolescents that go to school? Do not include school missed for routine medical appointments.**

**(ENDO\_MISSED\_SCHOOL)**

* Yes
* No
1. **This question has been removed from the survey.**
2. **Do you have a program for Type 2 diabetes patients such that they see each of at least four of the following providers for diabetes at least twice per year?**
	* **Endocrinology physician or Advanced Practice Provider (APP),**
	* **Diabetes RN educator,**
	* **Dietitian,**
	* **Social worker,**
	* **Psychologist,**
	* **Exercise physiologist or physical therapist,**
	* **Pharmacist**

**(ENDO\_TYPE2\_TEAM)**

* Yes
* No

SKIP LOGIC: IF C29.2a1 + C29.2a2 + C29.2b1 + C29.2b2 > 0, ASK C41 – C43. ELSE, GO TO C44.

1. **How many primary care diabetes Type 1 patients (include only patients reported in C29.2a) who are > 11 to < 19 years of age had a lipid panel measured in the last 3 calendar years ? Of those, how many had an LDL cholesterol less than 130 at the most recent measurement?** [Please report the values separately for patients covered by private/commercial insurance versus Medicaid only[[14]](#footnote-15).] [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Private Insurance** | **Medicaid Insurance** |
| a.  | Number of primary care Type 1 patients with lipid measurement in the last 3 years | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(ENDO\_T1DLDL\_MEASURED\_** | **PRIVATE)** | **MEDICAID)** |
| b.  | Number of primary care Type 1 patients with LDL < 130 at the last measurement | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(ENDO\_T1DLDL\_LESS130\_** | **PRIVATE)** | **MEDICAID)** |
|  |  |  |  |

NOTES: C41.1x should be whole number only. Do not allow decimals.

VALIDATE: IF C41b1 > C41a1, DISPLAY: “(Private Insurance) Number of Type 1 patients with LDL <130 (C41b) cannot be greater than number of Type 1 patients with any LDL measurement (C41a).”

 IF C41b2 > C41a2, DISPLAY: “(Medicaid Insurance) Number of Type 1 patients with LDL <130 (C41b) cannot be greater than number of Type 1 patients with any LDL measurement (C41a).”

 IF (C41a1 > C29.2a1): “Please check your responses. You reported more Type 1 patients 10 years of age with LDL measurements than primary Type 1 diabetes care patients with private insurance reported in C29.2. Please correct your response on this screen or use the navigation menu on the left to return to C29.2.”

 IF (C41a2 > C29.2a2): “Please check your responses. You reported more Type 1 patients 10 years of age with LDL measurements than primary Type 1 diabetes care patients with Medicaid reported in C29.2. Please correct your response on this screen or use the navigation menu on the left to return to C29.2.”

**C41.1 How many primary care diabetes Type 2 patients (include only patients reported in C29.2b) who are > 11 to < 19 years of age had a lipid panel measured in the last calendar year? Of those, how many had an LDL cholesterol less than 130 at the most recent measurement?** [Please report the values separately for patients covered by private/commercial insurance versus Medicaid only[[15]](#footnote-16).] [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Private Insurance** | **Medicaid Insurance** |
| a. | Number of primary care Type 2 patients with lipid measurement in the last year | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(ENDO\_T2DLDL\_MEASURED\_** | **PRIVATE)** | **MEDICAID)** |
| b. | Number of primary care Type 2 patients with LDL < 130 at the last measurement  | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(ENDO\_T2DLDL\_LESS130\_** | **PRIVATE)** | **MEDICAID)** |
|  |  |  |  |

NOTES: C41.1x should be whole number only. Do not allow decimals.

VALIDATE: IF C41.1b1 > C41.1a1, DISPLAY: “(Private Insurance) Number of Type 2 patients with LDL <130 (C41.1b) cannot be greater than number of Type 2 patients with any LDL measurement (C41.1a).”

 IF C41.1b2 > C41.1a2, DISPLAY: “(Medicaid Insurance) Number of Type 2 patients with LDL <130 (C41.1b) cannot be greater than number of Type 2 patients with any LDL measurement (C41.1a).”

**C41.2 How many primary care diabetes Type 2 patients who had lipid measurement in the last year (include only patients reported in C41.1a) had a triglyceride less than 150 at the most recent measurement?** [Please report the values separately for patients covered by private/commercial insurance versus Medicaid only[[16]](#footnote-17).] [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Private Insurance** | **Medicaid Insurance** |
| a.  | Number of primary care Type 2 patients with TG < 150 at the last measurement | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(ENDO\_TG\_MEASURED\_** | **PRIVATE)** | **MEDICAID)** |

1. **Does your hospital track seasonal influenza vaccination of primary diabetes care pediatric outpatients (see C29.2a and C29.2b) < 19 years of age who are currently in the care of your Pediatric Diabetes program?**

**(ENDO\_TRCK\_OUTPAT\_FLUVAC)**

* Yes
* No
1. **This question has been removed from the survey.**

**C44. This question has been removed from the survey.**

**C45. This question has been removed from the survey.**

1. **Does your hospital have the following multidisciplinary treatment programs on site at your hospital** **that manage the care of patients with the following conditions? If yes, do pediatric endocrinologists regularly attend the programs (i.e., at least monthly)?**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Yes, and Pediatric Endo regularly attends** | **Yes, but Pediatric Endo does NOT regularly attend** | **No program** |
| a. | Lipid disorders **(ENDO\_SPECIALCLINIC\_LIPID)** | ○ | ○ | ○ |
| b. | Comprehensive weight management **(ENDO\_SPECIALCLINIC\_WEIGHT)** | ○ | ○ | ○ |
| c. | Turner syndrome **(ENDO\_SPECIALCLINIC\_TURNER)** | ○ | ○ | ○ |
| d. | Cystic fibrosis-related diabetes **(ENDO\_SPECIALCLINIC\_CYSTIC)** | ○ | ○ | ○ |
| e. | Disorders of Sexual Development **(ENDO\_SPECIALCLINIC\_DISORDERS)** | ○ | ○ | ○ |
| f. | Thyroid nodules **(ENDO\_SPECIALCLINIC\_THYROID)** | ○ | ○ | ○ |
| g. | 22q11.2 Deletion Syndrome **(ENDO\_SPECIALCLINIC\_DELE)** | ○ | ○ | ○ |
| h. | Muscular Dystrophy **(ENDO\_SPECIALCLINIC\_MD)** | ○ | ○ | ○ |
| i. | Prader Willi Syndrome **(ENDO\_SPECIALCLINIC\_PRAD)** | ○ | ○ | ○ |
| j. | Pediatric Hematology or Oncology **(ENDO\_SPECIALCLINIC\_HEMONC)** | ○ | ○ | ○ |
| k. | Metabolic Bone Disease **(ENDO\_SPECIALCLINIC\_BONE\_DIS)** | ○ | ○ | ○ |

1. **Please indicate the number of unique pediatric patients seen in your Pediatric Endocrinology program as an outpatient in the last calendar year with the following diagnoses.** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Unique Patients** |
| a. | Congenital adrenal hyperplasia (see code list) **(ENDO\_CONGENITAL\_CAH)** | \_\_\_\_\_\_\_\_ |
| b. | CNS and Endocrine tumors (See code list) **(ENDO\_CONGENITAL\_CNS)** | \_\_\_\_\_\_\_\_ |
| c. | Diabetes insipidus (see code list) **(ENDO\_CONGENITAL\_DI)** | \_\_\_\_\_\_\_\_ |
| d. | Hypopituitarism including Panhypopituitarism, Growth Hormone Deficiency, TSH deficiency, ACTH deficiency, Gonadotropin Deficiency (see code list) **(ENDO\_CONGENITAL\_GROWTH)** | \_\_\_\_\_\_\_\_ |
| e. | Turner Syndrome (see code list) **(ENDO\_CONGENITAL\_TURNER)** | \_\_\_\_\_\_\_\_ |
| f. | Noonan Syndrome (see code list) **(ENDO\_CONGENITAL\_NOONAN)** | \_\_\_\_\_\_\_\_ |
| g. | Disorders of Sexual Development (see code list) **(ENDO\_CONGENITAL\_DISORDERS)** | \_\_\_\_\_\_\_\_ |
| h. | Bone Disease (including metabolic and genetic conditions) (see code list) **(ENDO\_CONGENITAL\_BONE)** | \_\_\_\_\_\_\_\_ |
| i. | Non-diabetes related hypoglycemia (see code list) **(ENDO\_CONGENITAL\_HYPOGLYCEMIA)** | \_\_\_\_\_\_\_\_ |
| j. | Poly Cystic Ovarian Syndrome (see code list) **(ENDO\_CONGENITAL\_POLY)** | \_\_\_\_\_\_\_\_ |

NOTES: C47x should be whole number only. Do not allow decimals.

1. **How many newly diagnosed patients with growth hormone deficiency or with multiple pituitary hormone deficiencies (see code list) that include growth hormone deficiency were seen by your Pediatric Endocrinology program in the last calendar year? Exclude patients with brain tumors (see code list).** [If none, please enter 0.]

\_\_\_\_\_\_\_\_ Unique Patients **(ENDO\_GROWTH\_NEW)**

NOTES: C48 should be whole number only. Do not allow decimals.

SKIP LOGIC: IF C48>0, ASK C49; ELSE SKIP TO C51.

1. **Of this group of newly diagnosed patients (identified in C48), how many received the following diagnostic or treatment measures?** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Unique Patients** |
| a. | A brain or pituitary MRI in the last 2 calendar years (see code list) **(ENDO\_GROWTH\_TREATMENT\_MRI)** | \_\_\_\_\_\_\_\_ |
| b. | Prescribed growth hormone therapy in the last calendar year (see code list) **(ENDO\_GROWTH\_TREATMENT\_THERAPY)** | \_\_\_\_\_\_\_\_ |
| c. | Serum IGF-1 measurement in the last calendar year (see code list) **(ENDO\_GROWTH\_TREATMENT\_IGF)** | \_\_\_\_\_\_\_\_ |

NOTES: C49 should be whole number only. Do not allow decimals.

VALIDATE: IF C49x > C48, DISPLAY: “The number of patients in C49x cannot be greater than the number of patients in C48.”

1. **This question has been removed from the survey.**
2. **Does your Pediatric Endocrinology program provide the following diagnostic/treatment options on site at your hospital?** [To answer yes, your program must have seen at least 1 unique patient for each procedure, in the last calendar year to meet the minimum patient volume requirement.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Diagnostic radioisotope scan (see code list) | **○** | **○** |
|  | **(ENDO\_DIAG\_** | **\_SCAN)** |
| b. | Therapeutic radioiodine treatment for Graves disease (see code list – must have both diagnosis and procedure code)  | **○** | **○** |
|  | **(ENDO\_DIAG\_** | **\_GRAVES)** |
| c. | Therapeutic radioiodine treatment for thyroid cancer (see code list – must have both diagnosis and procedure code)  | **○** | **○** |
|  | **(ENDO\_DIAG\_** | **\_THYROID)** |
| d. | Thyroidectomy (see code list) | **○** | **○** |
|  | **(ENDO\_DIAG\_** | **\_ECTOMY)** |
| e. | Intraoperative PTH assay (see code list) | **○** | **○** |
|  | **(ENDO\_DIAG\_** | **\_PTH)** |
| f. | Intravenous bisphosphonate therapy (see code list) | **○** | **○** |
|  | **(ENDO\_DIAG\_** | **\_IVBI)** |

**C51.1 This question has been removed from the survey.**

1. **This question has been removed from the survey.**
2. **This question has been removed from the survey.**

**C53.1. . This question has been removed from the survey.**

1. **Does your Pediatric Endocrinology program have a clinical endocrinology database (for non-diabetes patients) that is used by the program to evaluate quality performance?**

**(ENDO\_CLIN\_DATABASE)**

* Yes
* No

**C54.1. If “yes” to C54, please describe what patient metrics you follow in the database. [**To receive credit, you must identify what you measure and how this information is used by your program]:

|  |
| --- |
| **(ENDO\_QUALI\_DATABASE)** |

1. **This question has been removed from the survey.**
2. **Does your Pediatric Endocrinology program discuss all pediatric thyroid cancer patient cases in active treatment at a multidisciplinary conference (this may include a tumor board or other review process) attended by a Pediatric Endocrinologist with Pathology, Surgery, and Radiology also present?**

**(ENDO\_ACCTREATMENT)**

* Yes
* No
1. **Please indicate the number of unique patients in each of the following categories seen in your Pediatric Endocrinology program in the last calendar year.** [Note that your numbers may include all pediatric patients seen for care that are < 21 years of age.] [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Unique Patients** |
| a.  | Pediatric endocrinology outpatients excluding diabetes (see code list for exclusions) seen in the last calendar year  | \_\_\_\_\_\_\_\_ |
|  | **(ENDO \_LASTYR\_OUT\_** | **PATS)** |
| b.  | Pediatric endocrinology inpatients excluding diabetes (see code list for exclusions) seen in the last calendar year | \_\_\_\_\_\_\_\_ |
|  | **(ENDO \_LASTYR\_IN\_** | **PATS)** |

NOTES: C57x should be whole number only. Do not allow decimals.

1. **For all admissions to your hospital in the last year with a potentially severe endocrine disorder (including adrenal insufficiency, panhypopituitarism, diabetes insipidus: see code list), how many have an admission or consultation note written by a physician in your Pediatric Endocrinology program?** [Calculate as follows: (a.) Determine the total number of all admissions to your hospital with a potentially severe endocrine disorder (b.) Determine the number of these with an admission or consultation note written by a physician in your Pediatric Endocrinology program (c.) Clicking “Save” will calculate the percent by dividing the number of admissions with an admission or consultation note by the total number of admissions and multiplying by 100. Responses will be rounded to 2 decimals.]

\_\_\_\_\_\_\_\_ a. Number of admissions with a potentially severe endocrine disorder

**(ENDO\_SEENBY\_PHYS\_TOT)**

\_\_\_\_\_\_\_\_ b. Number with an admission or consultation note written by a physician

in your Pediatric Endocrinology program

**(ENDO\_SEENBY\_PHYS)**

\_\_\_\_\_\_\_\_c.Percent of admissions with an admission or consultation note

**(ENDO\_PCT\_SEENBY\_PHYS)**

NOTES: C58a and C58b should be whole numbers only. Do not allow decimals.

VALIDATE: IF C58b > C58a DISPLAY, “C58: The number of admissions with an admission or consultation note cannot be greater than the total number of admissions.”

AUTOCALC: C58c = [(C58b / C58a) \*100]

1. **Of the new congenital hypothyroidism patients (see code list) seen in your Pediatric Endocrinology program in the last calendar year, how many were in each of the following categories?** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **New Patients** |
| a.  | Had a confirmatory serum TSH >50 uIU/ml and were referred to Pediatric Endocrinology at < 21 days of age? **(ENDO\_CONHYP\_TSH)**  | \_\_\_\_\_\_\_\_ |
| b.  | Of the patients identified in C59a, how many began thyroid hormone therapy on or before 21 days of age? **(ENDO\_CONHYP\_BEFORE21)**  | \_\_\_\_\_\_\_\_ |

NOTES: C59x should be whole number only. Do not allow decimals.

VALIDATE: IF C59b > C59a, DISPLAY: Patients in C59b cannot be greater than patients in C59a.”

**C59.1 How many unique congenital hypothyroidism patients (see code list), > 3 months of age and < 3 years of age[[17]](#footnote-18) at the time of their last visit** **in 2024, were seen in your Pediatric Endocrinology outpatient clinic at least three times in the last calendar year? Of those, how many have at least 2 TSH values that fall within the normal range[[18]](#footnote-19) for that TSH assay?**

\_\_\_\_\_\_\_\_ a. Unique Patients with congenital hypothyroidism **(ENDO\_HYPO)**

\_\_\_\_\_\_\_\_ b. Unique Patients with at least 2 TSH values in normal range **(ENDO\_HYPO\_NORMTSH)**

NOTES: C59.1x should be whole number only. Do not allow decimals.

VALIDATE: IF C59.1b > C59.1a, DISPLAY: Number of Patients with at least 2 TSH values in normal range cannot be greater than number of patients with congenital hypothyroidism.”

**C59.2 Of the unique patients newly diagnosed with Grave’s Disease (see code list) who were seen in your Pediatric Endocrinology program in the last calendar year, how many have had at least one Free T4 value fall within the normal range**[[19]](#footnote-20) **for during the 3 months after diagnosis?**

**(ENDO\_GRAVES\_NORMTSH)**

* + 0-69%
	+ 70-79%
	+ 80-89%
	+ 90-100%
* NA. Did not see Grave’s Disease patients for Free T4 screening in the last calendar year. **(ENDO\_GRAVES\_NORMTSH\_NA)**

NOTES: N/A should be mutually exclusive (i.e. cannot be selected with other responses).

1. **Does your Pediatric Endocrinology program take a leadership role in organizing or supporting family support groups for special populations other than diabetes (e.g., Turner syndrome, DSD, 22q11, transgender)?**

**(ENDO\_LEAD\_SUPPORT)**

* Yes
* No
1. **This question has been removed from the survey.**
2. **This question has been removed from the survey.**
3. **Does your Pediatric Endocrinology Program have a system in place to alert providers that the following types of patients have not returned for care (exam and/or laboratory tests) after an agreed upon time interval since their last visit?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Type 1 and Type 2 diabetes **(ENDO\_RETURN\_TYPE1)** | ○ | ○ |
| b. | Congenital hypothyroidism **(ENDO\_RETURN\_CHT)** | ○ | ○ |
| c. | Congenital adrenal hyperplasia **(ENDO\_RETURN\_CAH)** | ○ | ○ |
| d. | Growth hormone therapy **(ENDO\_RETURN\_GHT)** | ○ | ○ |
| e. | Precocious puberty on therapy **(ENDO\_RETURN\_PUBERTY)** | ○ | ○ |
| f. | Hyperthyroidism on anti-thyroid medication **(ENDO\_RETURN\_HYPER)** | ○ | ○ |

**C64. This question has been removed from the survey.**

1. **How many of the following types of conferences or educational programs did your Pediatric Endocrinology program host or conduct in the last calendar year?** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Number of Conferences** |
| a.  | Joint case conferences with your institution’s Internal Medicine Endocrinology program **(ENDO\_HOST\_INTERNALMED)** | \_\_\_\_\_\_\_\_ |
| b.  | Joint case conferences with your institution’s Genetics program **(ENDO\_HOST\_GENETICS)** | \_\_\_\_\_\_\_\_ |
| c.  | Pediatric Endocrinology case conference **(ENDO\_HOST\_CASE)** | \_\_\_\_\_\_\_\_ |
| d.  | Pediatric Endocrinology journal club **(ENDO\_HOST\_JOURNAL)** | \_\_\_\_\_\_\_\_ |
| e.  | CME-granting educational activity or conferences **(ENDO\_HOST\_CME)** | \_\_\_\_\_\_\_\_ |
| f. | Morbidity and Mortality or Review of Safety Issues conference **(ENDO\_HOST\_MORBID)** | \_\_\_\_\_\_\_\_ |

NOTES: C65x should be whole number only. Do not allow decimals.

1. **This question has been removed from the survey.**
2. **Please indicate the number of IRB-approved clinical research studies or trials, in which a clinician from your program was PI or Co-PI, that are either physiologic studies or give patients access to novel, unlabeled medications, or diagnostic/monitoring devices or treatments options. Include only studies that are currently active.**

**(ENDO\_TRIALS)**

* 0 trials
* 1-6 trials
* 7-11 trials
* 12 or more trials
1. **For the study or studies counted above, please list the NCT number for one trial. If no NCT available, please provide an explanation:**

|  |
| --- |
| **(ENDO\_NCT)** |

**The following are being collected for information purposes only. They will not be factored into the rankings this year.**

**C69. Does your hospital track Pneumovax vaccination of primary diabetes care pediatric**

**outpatients (see C29.2a and C29.2b) < 19 years of age who are currently in the care of your**

**Pediatric Diabetes program?**

**(ENDO\_TRCK\_OUTPAT\_PNEUVAC)**

* Yes
* No – Skip to Question C71

**C70. This question has been removed from the survey.**

**C71. Does your Pediatric Diabetes program have a written consensus protocol or guidelines for teplizumab administration?**

**(ENDO\_PROTOCOL\_PRESX)**

* Yes
* No

**C72. Please indicate whether 1 or more pediatric patients were seen in your Pediatric Endocrinology program as an outpatient in the last calendar year with Stage 1 or Stage 2****[[20]](#footnote-21) Type 1 diabetes.** [If none, please enter no.]

**(ENDO\_OUTPT\_T1S1S2)**

* Yes
* No

**CHIEF OF SERVICE APPROVAL**

To have this section of the survey accepted for scoring, the Service Chief for your Pediatric Endocrinology program must acknowledge that they have reviewed all responses and approve of the submission. To do this you will need to download, complete, and upload the approval form by the date of the final survey submission. Has the approval form for your Pediatric Endocrinology program been completed and uploaded to the Pediatric Hospital Survey website?

**(ENDO\_DIR\_APPROVE)**

* Yes, the form as been submitted
* No, the form has not been submitted. Please complete and upload the form before proceeding.

**COMMENTS FOR SECTION C:**

If needed, you may provide clarifications to the responses you provided to the questions asked in this section only. All other comments, suggestions or questions should be sent to PediatricHospSurvey@rti.org.

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| --- |
| **(ENDO\_COMMENTS)** |

1. Attending/on-staff physicians include those who have completed their training in their particular medical specialty or subspecialty, are actively providing clinical care to patients, and are currently considered a member of the “medical staff” at the hospital. This may include physicians employed by the hospital, an affiliated university, or some other entity as long as the physician is considered part of the medical staff at the hospital. [↑](#footnote-ref-2)
2. Calculate nurse and other staff FTEs based on total paid hours for the period of review divided by 2080. [↑](#footnote-ref-3)
3. For members of your staff, count only staff that your hospital provides. Exclude educators or trainers provided by the device manufacturers or suppliers. [↑](#footnote-ref-4)
4. Formal advocacy effort means working with local, state, or federal policy makers to advocate for change in policy, regulations, or laws to support the rights of patients with diabetes. For example, a hospital could work with a local school district to change policy to allow blood glucose monitoring and insulin administration in every school building. [↑](#footnote-ref-5)
5. For these questions, primary diabetes care pediatric outpatients refer to actively managed patients for which the program has assumed the primary responsibility for their diabetes care – not merely as consultants. [↑](#footnote-ref-6)
6. If patient has both commercial/private insurance and Medicaid, then count them as having private insurance. If patient is self-pay, or if Medicaid is pending, then count them as Medicaid patients. If patient is covered by a state “handicapped children’s fund” then count them according to any other insurance source, or Medicaid if there is no other insurance source. [↑](#footnote-ref-7)
7. If you had a patient seen in the emergency room and then admitted, please count them in C/D. E/F is separate and is only looking for patients that were seen in the emergency room and sent home. [↑](#footnote-ref-8)
8. If a patient is seen in ED or urgent care and subsequently admitted, count only the admission and not the ED visit. [↑](#footnote-ref-9)
9. Note that Type 2 diabetes patients should be evaluated since the age of diagnosis rather than after the age of 10. Make sure you update the criteria when pulling these records so that you include all Type 2 diabetes patients in the eligible population. [↑](#footnote-ref-10)
10. Adequate diabetes management is defined as having at least one Hemoglobin A1c at or below 7.5% in the last calendar year. [↑](#footnote-ref-11)
11. Telemedicine visits that include a documented history, including review of blood glucose data, and a documented action plan qualify as an outpatient clinic visit and may be counted in this response. Clinic visits that do not involve a physician, NP, or PA but do include a documented history, including review of blood glucose data and a document action plan qualify as an outpatient clinic visit. [↑](#footnote-ref-12)
12. Please use age at encounter if available. Otherwise, use age on a set date for all items. [↑](#footnote-ref-13)
13. If patient has both commercial/private insurance and Medicaid, then count them as having private insurance. If patient is self-pay, or if Medicaid is pending, then count them as Medicaid patients. If patient is covered by a state “handicapped children’s fund” then count them according to any other insurance source, or Medicaid if there is no other insurance source. [↑](#footnote-ref-14)
14. If patient has both commercial/private insurance and Medicaid, then count them as having private insurance. If patient is self-pay, or if Medicaid is pending, then count them as Medicaid patients. If patient is covered by a state “handicapped children’s fund” then count them according to any other insurance source, or Medicaid if there is no other insurance source. [↑](#footnote-ref-15)
15. If patient has both commercial/private insurance and Medicaid, then count them as having private insurance. If patient is self-pay, or if Medicaid is pending, then count them as Medicaid patients. If patient is covered by a state “handicapped children’s fund” then count them according to any other insurance source, or Medicaid if there is no other insurance source. [↑](#footnote-ref-16)
16. If patient has both commercial/private insurance and Medicaid, then count them as having private insurance. If patient is self-pay, or if Medicaid is pending, then count them as Medicaid patients. If patient is covered by a state “handicapped children’s fund” then count them according to any other insurance source, or Medicaid if there is no other insurance source. [↑](#footnote-ref-17)
17. Note that the <3 years of age restriction applies to all qualifying visits for this question. [↑](#footnote-ref-18)
18. Note that the normal range varies from lab to lab. Please use the normal range standard your hospital uses with your current TSH testing lab. [↑](#footnote-ref-19)
19. Note that the normal range varies from lab to lab. Please use the normal range standard your hospital uses with your current Free T4 testing lab. [↑](#footnote-ref-20)
20. Both Stage 1 and Stage 2 diabetes are individuals that have two or more positive islet cell antibodies but do not meet the ADA definition of stage 3 diabetes (A1c > 6.5, 2 hour OGTT >200, or consistent fasting BG > 126). [↑](#footnote-ref-21)